Examining the National Representativeness of the Axon Registry: A Neurology-Specific Patient Registry

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Abstract:

Objective: To determine the external validity of the Axon Registry by comparing the 2019 calendar year data to two nationally representative, publicly available data sources, specifically the National Ambulatory Medical Care Survey (NAMCS) and the Medical Expenditure Panel Survey (MEPS).

Background: The Axon Registry is the American Academy of Neurology’s neurology-focused qualified clinical data registry that reports and analyzes electronic health record data from participating US neurology providers. Its key function is to support quality improvement within ambulatory neurology practices while also promoting high quality evidence-based care in clinical neurology. We compared demographics for patients who had an outpatient or office visit with a neurologist along with prevalence of selected neurological conditions and neurological procedures across the three datasets.

Design/Methods: We performed a cross-sectional, retrospective comparison of three datasets: NAMCS (2012-2016), MEPS (2013-2017, 2019), and Axon Registry (2019). We obtained patient demographics (age, birth sex, race, ethnicity), patient neurological conditions (headache, epilepsy, cerebrovascular disease, multiple sclerosis, parkinsonism, dementia, spinal pain, and polyneuropathy), provider location, and neurological procedures (neurology visits, MR/CT neuroimaging studies and EEG/EMG neurophysiological studies). Parameter estimates from the pooled five-year samples of the two public datasets, calculated at the visit-level, were compared descriptively to those of the Axon Registry. We calculated Cohen’s $h$ and performed Wald tests (alpha=0.05) to conduct person-level statistical comparisons between MEPS 2019 and Axon Registry 2019 data.
**Results:** The Axon Registry recorded 1.3M annual neurology visits (NAMCS, 11M; MEPS, 22M) and 645K people with neurological conditions (MEPS, 10M). Compared to the pooled national surveys, the Axon Registry has similar patient demographics, neurological condition prevalence, neuroimaging and neurophysiological utilization, and provider location. In direct comparison to MEPS 2019, the Axon Registry 2019 had fewer children (2% vs. 7%), more elderly persons (21% vs. 16%), fewer non-Black, non-White race persons (5% vs. 8%), less epilepsy (10% vs. 13%), more dementia (8% vs. 6%), more cerebrovascular disease (11% vs. 8%), and a greater predominance of neurology providers in the Midwest (25% vs. 20%). The only difference with a non-negligible effect size was the proportion of people < 15 years of age (Cohen’s $h$=0.25).

**Conclusions:** The Axon Registry demonstrates high concordance with two nationally representative surveys. Recruiting more and diverse neurology providers will further improve the volume, representativeness, and value of the Axon Registry.
Introduction:

Clinical data registries are a powerful and promising tool to collect routine data generated from patient care visits.\textsuperscript{1,2} Registries can facilitate public reporting, foster quality improvement, and reveal new discoveries.\textsuperscript{3} As registry data is not a random sampling of the populations of interest, registries must be critically examined to determine their validity and generalizability in order to make appropriate inferences about the data they support.\textsuperscript{4}

The Axon Registry is owned by the American Academy of Neurology Institute (AAN), and its purpose is to collect, report, and analyze electronic health record (EHR) data from participating neurology providers in the US.\textsuperscript{5} Its key function is to support quality improvement within neurology practices and to enhance evidence-based care in the field of clinical neurology.\textsuperscript{6,7} Registries are prospectively designed and collected repositories of data intended to address patient populations and care areas that may not be covered by either clinical trials or retrospective administrative claims studies.\textsuperscript{4} Beginning with registries intended to study the clinical course of very rare diseases,\textsuperscript{8,9} registries have expanded more broadly to assess quality of care in areas such as surgery (the National Surgery Quality Improvement Program\textsuperscript{10,11} and the National Neurosurgery Quality Outcomes Database\textsuperscript{12,13} from the American College of Surgery and the Congress of Neurological Surgeons, respectively) and imaging (National Radiology Data Registry\textsuperscript{14,15} from the American College of Radiology). The Axon Registry, like these other datasets, can potentially assess effectiveness of specific metrics and guidelines for patients and practices in the real world.\textsuperscript{16} This goal is only fully realized when results and outcomes pertain beyond the subset of patients covered by the registry to the greater patient population seen by neurologists at a national level.
As a voluntary registry of US neurology providers, the Axon Registry is a convenience sample where incentives for participation in the registry may lead to data that is not representative of the underlying population (i.e., all patients seen by US neurology providers in an ambulatory setting). To assess this selection bias, we examine the external validity and the generalizability of the Axon Registry by comparing its data to two nationally representative, publicly available data sources, the National Ambulatory Medical Care Survey (NAMCS) and the Medical Expenditure Panel Survey (MEPS). Both MEPS and NAMCS are constructed to yield statistically valid estimates of US patient and provider characteristics and serve as viable reference points for visit-level and person-level comparisons to the Axon Registry data. In line with the broader effort to report on the data quality of registries and the robustness of evidence they generate\textsuperscript{17-19}, the objective of this paper is to describe the representativeness of the Axon Registry by (1) descriptively comparing visit-level demographic and healthcare utilization information between Axon Registry 2019 and pooled MEPS & NAMCS data and (2) statistically compare person-level demographic and healthcare utilization information between Axon Registry 2019 and MEPS 2019 data.

**Methods**

**Study Design**

This is a retrospective, cross-sectional observational study examining person and visit-level characteristics of patients seeing US neurologists in ambulatory care in three datasets: Axon Registry, NAMCS, and MEPS.
Standard Protocol Approvals, Registrations, Patient Consents and Data Privacy

Patient and provider data were collected, used, and secured in a lawful manner by the Axon Registry to assist with the health care operations of the participants. The use of Axon Registry data was in accordance with the Privacy Statement for AAN-Generated Axon Registry Publications. Only de-identified data derived from the Axon Registry was accessed and analyzed for this study. Specifically, Verana Health provides authorized AAN staff access to the registry’s de-identified database, which does not require any special request. Authorized AAN staff, run data queries and perform analyses on this de-identified database and share results with collaborating partners. For this project, AAN staff were both analysts and authors. Per 45 CFR part 46, secondary data analysis of de-identified data does not constitute human subjects research and does not require institutional review board (IRB) review. We constructed the analysis in accordance with the STrengthening the Reporting of OBservational studies in Epidemiology (STROBE) guidelines.

Data Sources:

Axon Registry

The Axon Registry dataset launched in 2015, and by 2019 comprised data from 139 US neurology practices and 1,023 neurology providers (neurologists and advanced practice providers). The Axon Registry reports neurology-specific clinical quality process and outcome measures obtained via EHR information from participating neurology practices and is maintained by Verana Health, AAN’s data and technology partner. Details of the development, validation, and measures of the Axon Registry have been reported previously. The data for
this project was limited to the 2019 calendar year as it reflected the most recent year of data following a comprehensive data validation and quality control process by AAN staff, AAN (sub)committee members, and Verana Health. This included deduplication of records, assessment of the completeness, accuracy, and timeliness of the data, review of the distribution of individual elements, curation, and normalization of variables, as well as tokenization and de-identification.

Data Availability

The underlying patient or provider identifiable data submitted to the Axon Registry for health care operations in the normal course of clinical care are not available due to privacy and contractual restrictions. The aggregate, de-identified data used for this study are available on request from authorized investigators. The Axon Registry measure glossary can be found online.

Public Data Sources

We examined pooled multiyear data from two publicly available data sources where care provided by a neurologist could be identified. First, we used the MEPS, a dataset compiled and maintained by the Agency for Healthcare Research and Quality that is publicly available for healthcare researchers. MEPS consists of approximately 30,000 annual respondents who participate in the survey for two years and represent the non-institutionalized population of the United States in each year. Respondents complete detailed queries about their medical conditions and healthcare utilization, which are coded and logged by qualified technicians and verified with medical records and claims review whenever possible. MEPS has annual full-year and component event files, as well as linkage files and annual and longitudinal pooled survey
files for creation of accurate national-level estimates and variances at both the visit- and person-level. MEPS further assigns diagnostic coding to each incident of healthcare utilization. We pooled the annual cross-sectional data for panels 17-23, which includes the years 2013-2017, and separately looked at data corresponding to a single calendar year, 2019.

Second, we utilized cross-sectional data pooled from NAMCS between 2012-2016, comprising the latest five years where physician visits were identifiable by specialty. NAMCS is an annual survey conducted by the National Center for Health Statistics using a sample of office-based medical care visits from non-federal physicians. Physicians and/or medical office staff are instructed on how to participate in the survey, which involves filling out a standardized encounter form for a random sample of patient visits during a one-week time frame. Patient visit level information, including patient demographics, clinical conditions, diagnostics and therapies administered are collected, as are physician-level data including geographic location and physician specialty. The resulting data is probability weighted to reflect likelihood of patient sampling and physician sampling within the United States, with stratification and clustering variables for accurate standard errors. Annualized probability weights in both MEPS and NAMCS samples were adjusted based on the number of pooled sample years.

Case Identification, Data Extraction, and Variable Construction

From the Axon Registry, we identified outpatient/office-based visits to a neurologist in the calendar year 2019 using Current Procedural Terminology-4 (CPT®) Evaluation and Management codes (range 99202 to 99215) and Consultation codes (99241-99245). While Axon Registry does record performance for neurology employed advance practice providers, that
data was excluded from the current paper to allow direct comparison to physicians in other databases. Associated patient demographics (age, birth sex, race, ethnicity), neurology provider characteristics (geographic location), and select neurological conditions and diagnostic procedures (EEG, MR/CT, and EMG) were also collected.

In NAMCS, we identified patients who had seen a neurologist in an ambulatory care setting. We extracted patient demographic variables (age, birth sex, race, ethnicity) and clinical diagnoses from International Classification of Disease ninth revision (for years 2012-2015) and tenth revision (year 2016) (ICD-9, ICD-10) diagnostic coding associated with the visit, as well as any advanced neuroimaging (MR/CT) and neurophysiological studies (EEG/EMG) ordered. The US Census Bureau region where the visit occurred was also extracted.

In MEPS, we identified patients who had at least one neurologist visit in the office-based and outpatient event files. We extracted patient demographics and geographic variables from the annual consolidated files and linked ICD-9 and ICD-10 diagnostic codes in the annual medical conditions file to each visit. We reported outpatient procedures for EEG (variable in 2013-2015, data not recorded in subsequent years) and advanced neuroimaging (MR/CT). Notably, geographic information (again, US Census Bureau Region) for MEPS refers to the address of the survey respondent (person), rather than the location where a particular visit occurred.

We constructed the following variables for each dataset: age was dichotomized into six categories (<15 years, 15-24, 25-44, 45-64, 65-74, >=75). Race was grouped into White, Black or African American, and Other (Asian, American Indian and Alaska Native, Native Hawaiian and Other Pacific Islander, Other Race). The rationale for aggregating these other racial groups in the Axon Registry is small sample size and de-identification concerns. Ethnicity was either
Hispanic or non-Hispanic. Geographic region was defined by the US Census Bureau region (Northeast, South, Midwest, West). Neurological conditions were grouped into eight categories defined by Clinical Classification Software (CCS) groupings of ICD-9 and ICD-10 codes for headache, epilepsy, cerebrovascular disease, multiple sclerosis, parkinsonism, dementia, spinal pain, and polyneuropathy (eAppendix 1 provides a listing of disease related codes used to identify these conditions).

Data Missingness

We determined the proportion of missing data by dataset from coding within the data sources and from data documentation for relevant variables and variable categories indicating missingness and imputation efforts, where appropriate. Imputation rates that are discussed, but not given quantitative values, are indicated. Missingness is not included in the estimates in primary data analysis but is reported separately.

Data Analysis

We examined data using two units of analysis: by visit and by person. We used pooled five-year data from NAMCS and MEPS to document the characteristics of individual visits to neurologists. Pooling multiple calendar years functions to increase the sample sizes sufficiently to give estimates for the characteristics of neurologist visits, which may have more variability than a person-level analysis. NAMCS only allows estimation of visit characteristics, rather than the characteristics of persons who see neurologists on multiple occasions. Both NAMCS and MEPS pooled data were re-weighted to provide annualized estimates (five years weighted to a single year) while using the survey-design variables for clustering and stratification. For the
Axon Registry dataset, which has a sufficient number of uniquely contributing individuals, we computed contingency tables of the categorical variables (see eAppendix 2). We opted to create a descriptive analysis only (including the survey-adjusted 95% confidence intervals for estimates from the multiyear pooled datasets) for corresponding variables in each of the three datasets, avoiding hypothesis testing that would not account for temporal trends (comparison of data from differing calendar years). We conducted a person-level analysis in the same calendar year of Axon Registry 2019 patients and MEPS 2019 respondents who saw a neurologist in office-based or outpatient care.

Using the Wald test of non-linear hypothesis, adjusted for survey design degrees of freedom, we developed an inferential analysis for comparable variables within the Axon Registry and the MEPS at the person-level in order to test the null hypothesis that the estimates for patients in MEPS 2019 are not significantly different than those in Axon Registry 2019.\textsuperscript{32, 33} We also computed Cohen’s $h$ to describe the “meaningfulness” (or practical significance, which is distinct from statistical significance) of the difference between the proportions for comparable variables within MEPS and the Axon Registry 2019. We followed a rule of thumb that $h<0.2$ represents a negligible effect size and that $0.2<h<0.5$ represents a small effect size.\textsuperscript{34} We used survey stratification, clustering, and probability weights to construct Taylor linearized standard errors and national-level estimates for the patient and visit level analyses from the NAMCS and MEPS data. All analyses were performed with Stata 16, (StataCorp, College Park, Tx.)
Results:

Visit-Level Analysis in Axon Registry 2019, MEPS 2013-2017, and NAMCS 2012-2016:

The Axon Registry reported a total of 974,161 outpatient and office-based visits to 1,033 neurologists in 158 practices in 2019. NAMCS 2012-2016 reported just over 4000 visits to a neurologist over 5 calendar years, while MEPS 2013-2017 reported 14,000 neurologist visits. Pooled data yielded estimates of 29 million average annual visits (95% CI 27, 31m) in MEPS, and 11 million annualized visits in NAMCS (Figure 1).

Demographic and Geographic Variables:

Demographics of those patients captured within the neurology visit reporting were similar in all datasets. Females accounted for the majority of visits for each dataset, with adults comprising over 90% of each sample. The elderly (persons over age 65) was represented in 42% of Axon Registry visits, an older population than both pooled NAMCS estimate (32%; 95% CI 29%, 35%) and the estimate from MEPS (38%, 95% CI 35%, 41%). Racial distribution was nearly identical in the three datasets, with a slightly larger proportion of Black persons in the Axon Registry (11%) than NAMCS (8%, 95% CI 6%, 10%), and similar rates of neurologist visits by Whites and non-Black (Asian, Pacific Islander, and Indigenous) persons in the Axon Registry, NAMCS, and MEPS. Geographic areas represented were most notably different in the Western census bureau region, where the Axon Registry had a smaller proportion of neurologist visits (16%) than either MEPS (20%; 95% CI 18%, 22%) or NAMCS (25%; 95% CI 22%, 28%) (Figure 2)
Clinical and Utilization Variables:

The clinical diagnoses seen in the Axon Registry dataset were more consistent with estimated proportions seen in NAMCS than in MEPS, particularly in headache, multiple sclerosis, dementia, and spinal pain. The exception was Parkinson’s disease, where MEPS and Axon Registry were more concordant. The percentages of neurologist visits in Axon Registry were larger than either NAMCS or MEPS pooled data national estimates for cerebrovascular disease (11% in Axon Registry, 4% in MEPS (95% CI 3%, 5%), 6% in NAMCS (95% CI 5%, 8%)), spinal pain (24% in Axon Registry, 13% in MEPS (95% CI 11%, 14%), 18% in NAMCS (95% CI 13%, 23%) and polyneuropathy (8% in Axon Registry, 1% in MEPS (95% CI 0%, 2%), 4% in NAMCS (95% CI 3%, 5%)).

Relative to NAMCS, the Axon Registry reported a lower MR/CT utilization rate (6% vs. 15%; 95% CI 7%, 23%) but a near identical EEG rate (6% vs. 5%; 95% CI 1%, 8%) and EMG rate (8% vs. 9%; 95% CI 5%, 16%). MEPS had a similar MR/CT utilization rate (5%; 95% CI 4%, 6%) but a lower EEG rate (2%; 95% CI 2%, 3%) than the Axon Registry. New visits and EMG were not assessed in MEPS (Figure 3).

Person-level Analysis in Axon Registry 2019 and MEPS 2019:

The Axon Registry reported 645,127 patients with at least one ambulatory visit to a neurologist in 2019. In 2019, 924 survey respondents in MEPS reported seeing a neurologist in office-based or outpatient care. This corresponds to a weighted estimate of 10.0 million persons seeing a neurologist in ambulatory care in the United States in 2019 (95% CI 9.2m, 11.0m; Figure 1).

Compared to MEPS 2019, the Axon Registry had a similar sex and ethnicity distribution. The Axon Registry had a lower percentage of non-White, non-Black race than in MEPS national
estimates (5% vs. 8%; 95% CI 6%, 10%; p=0.001) and a lower percent of children (2% vs. 7%; 95% CI 5%, 9%; p<0.0001). Of the 8 neurological conditions, Axon Registry differed from MEPS national estimates by a lower percentage of persons with epilepsy (10% vs. 13%; 95% CI 10%, 15%; p=0.04) and higher percentage with cerebrovascular disease (11% vs. 8%; 95% CI 6%, 9%; p<0.001) and dementia (8% vs. 6%; 95% CI 4%, 8%; p=0.01). Rates of advanced imaging utilization were not different in Axon Registry and MEPS in 2019. Axon Registry reported a greater percent of patients in the Midwest Census Bureau Region than in MEPS estimates (25% vs. 20%; 95% CI 18%, 23%; p<0.001; Table 1). The practical difference (in contrast to statistical difference) between the above proportions were all negligible (Cohen’s $h<0.2$) with the exception of the proportion of people <15 years of age ($h=0.25$).

**Missingness:**

Axon Registry had comparable rates of missing data to NAMCS and MEPS with some notable exceptions (Table 2). Age was collected for all visits/persons in Axon Registry, and an imputed value was given for less than 1 in 1000 survey respondents in MEPS. Birth sex was coded as a binary in each of these datasets and was imputed at a rate not reported in MEPS or NAMCS. Race and Ethnicity were missing in one fourth and greater than a third of persons in Axon Registry, a rate comparable to that seen in NAMCS (33% and 36%). Again, these values were imputed when missing at a non-reported rate in MEPS. Geographic Census information was present in all NAMCS and Axon Registry data and missing in 0.4% of persons with visits to a neurologist in MEPS 2019, a slightly higher value than the pooled MEPS 2013-2017 data. Diagnostic coding was missing in 5-8% of persons with neurologist visits in NAMCS and MEPS, with no missing data in the Axon Registry 2019 data. CPT coding was present for all persons in Axon Registry 2019 for procedures, while MEPS lacked coding for EMG in all data.
years and EEG in years after 2015; the value presented for the latter was based on 2013-2015 data only for the pooled MEPS 2013-2017 analysis. Advanced imaging (MR/CT) categorical data was lacking in less than 2% of MEPS data. NAMCS did not have missing data for any of the above procedures, nor was there imputation of procedural data in available documentation.

Discussion:

We examine provider and visit-level characteristics for the Axon Registry, a dataset which extracts information from neurologist ambulatory care visits, by comparing them to similarly identified persons in two separate datasets, NAMCS and MEPS. We show that visits in Axon Registry, including patient demographics and clinical conditions, are demonstrably similar to the estimates from the multiyear pooling of each of the two public datasets, and that patients in Axon Registry are not generally different (statistically or meaningfully) than their counterparts in MEPS in the 2019 data year. The following paragraphs expound upon a few key differences.

We found that patients within the Axon Registry skew slightly older than the nationally representative public datasets. The effect of age is likely the reason that diseases of the elderly, including cerebrovascular disease and dementia, are represented at higher rates within the Axon Registry, while epilepsy, a condition that has a bimodal age distribution, is less reported in our person-level analyses. The dearth of pediatric neurology participants of Axon Registry, who would contribute the portion of their patient panel below age 15 in this analysis, is hypothesized to be one driver of the epilepsy and youth estimate discordance. While not replicated in the person-level analysis, the higher proportion of back pain and polyneuropathy in the visit-level analysis may reflect the private practice, general neurology bend of Axon Registry providers.
who may spend more time addressing or thoroughly coding these common, chronic neurological pain conditions.

Also, we found greater representation of persons from the Midwest and less representation of neurologist visits in the West in the Axon Registry than in the public datasets. The geographic distribution of providers and practices contributing data to the Axon Registry may be related to the organic growth of the registry. Axon Registry was developed by the AAN, headquartered in Minnesota, and as an organization, the AAN has cultivated strong local bonds, which may have allowed for earlier recruitment of geographically proximate practices and providers (Figure 4). Outside of the Midwest, and especially along the coasts, greater consolidation of healthcare networks may have slowed the early adoption of the Axon Registry compared to smaller physician practices that rely on Axon Registry to submit data for quality payment programs, such as the Merit-Based Incentive Payment (MIPS). This geographic feature likely impacted demographics, as Asians and Pacific Islanders are less concentrated in the Midwest, leading to underrepresentation in the Axon Registry. Unfortunately, the imprecision around “Other Race” across the three datasets did not allow us to determine which subpopulation(s) was driving racial underrepresentation, but it is worth emphasizing that underrepresentation of non-White persons within Axon Registry threatens to hide or worsen the inequalities in the utilization of neurologic care already seen in MEPS.

The visit level analysis highlights some additional similarities and differences in clinic and procedure utilization between the Axon Registry and the other two datasets. NAMCS and Axon Registry, both derivatives of physician-provided data, have good agreement. The proportion of
new compared to established patients is similar in the two groups, and EMG, EEG, and MR/CT estimates in NAMCS are more consistent with the values given in Axon Registry, which are all higher than the point estimates of MEPS. The Axon Registry tracks the ordering of procedures through the EHR, rather than relying on patient-reported information, such as in MEPS, which may consequentially result in the capture of fewer services from neurologist visits, does not distinguish between new and established patients, and has less information on neurological procedures (no EMG data and EEG data only before 2016). Therefore, we suggest that the Axon Registry provides a more complete accounting of neurological and neurophysiologic services provided than MEPS.

Beyond the demographic and healthcare utilization comparisons, our study examines missingness of data elements and coverage of the target population relative to public datasets. These examinations are an essential component of registry quality assessment to produce valid inferences.4, 19, 39 First, Axon Registry comprised 7% (645k/9.2M) of all persons who received ambulatory care from neurologists in the United States in 2019. Second, the degree of missingness in demographic and geographic data compares favorably to the government provided data sources.

Due to its large size, granularity, and timeliness, the Axon Registry carries considerable advantages in examining the practice of neurology. The large sample size of Axon Registry, representing more than half a million patients and nearly a million visits to neurologists with full ICD and CPT coding, allows for more nuanced analyses for conditions that neurologists treat and services they order and provide. The Axon Registry follows patients over time, reporting the
evolution of diagnoses and management within a calendar year and beyond. Lastly, due to the near instantaneous mechanism of acquisition, Axon Registry data are more contemporaneous for analysis to address the effects of new policies and external disturbances to practice (i.e. ongoing effects of COVID), whereas data from government agencies (CMS, AHRQ, CDC) generally lags at least two years after data collection until general release.  

There are a number of limitations to this analysis. We acknowledge that comparison of variables of interest among the three datasets may be limited by different collection mechanisms for source data, including the use of imputation for missing data in NAMCS and MEPS. This highlights that even datasets that have existed and been refined for decades are imperfect but are routinely used to provide accurate national estimates for patients, conditions, and healthcare utilization. A direct comparison of Axon Registry for these estimates is likewise imperfect, where we use broader categories that exist in all three datasets for comparison. We use the CCS diagnostic groupers for general categories of diagnoses as detailed ICD codes are not available in all data (MEPS uses 3-digit codes); geographic variables apply to physician practices in NAMCS and Axon Registry and patient addresses in MEPS. This potentially creates a small discrepancy at the Census Bureau Region level that would be larger if a more granular measure were used. For the visit-level analysis, we opted against hypothesis testing as neither pooled dataset included the Axon Registry calendar year, so our analysis was purely descriptive. We contend this still has value, particularly for NAMCS, a provider-reported dataset, in describing visits to neurologists, both in terms of patients and conditions, but also utilization of neurologist-ordered services. Further, we did not formally test or estimate the selection bias that occurs from the non-random decision of a neurology provider or practice to join Axon Registry. Ideally, this approach would measure information about providers that explains their Axon Registry status. Without this, an
assurance statement about a nationally representative sample of providers or patients is premature. Finally, we compared population estimates of the common variables, which were limited to broad categories in demographics, geography, clinical disorders, and procedure utilization available in public datasets. We encourage datasets owners, including the AAN of the Axon Registry, to promote the inclusive and systematic collection and reporting of more nuanced information about socially-constructed identities (including but not limited to race, sexual orientation, gender identity, ability, and socioeconomic status) to better understand health and healthcare. Examination of costs or other outcomes was outside the scope of this analysis. Substantive provider-level information is lacking in all three datasets; though we encourage the Axon Registry to link to provider information in the future.

In conclusion, we find good agreement between currently accepted methodology for national-level estimates and the patients and conditions in the Axon Registry. Where the Axon Registry data differs from the expected values, there is greater room for improvement in recruiting a more diverse set of neurology practices contributing data to the Axon Registry, particularly in pediatric neurology and in the West Census region. Nevertheless, our study demonstrates that the Axon Registry data is among the largest, most granular data sources for patients and practices in neurology, with implications for both quality improvement of neurology practice and timely research and analysis in neurological conditions.
Figure 1. Flow Diagram for Visit-Level and Person-Level Analyses. NAMCS and MEPS provide national weighted estimates while Axon Registry does not. (n=unweighted persons, N(wt)=weighted estimated persons, v=unweighted visits, V(wt)=weighted estimated visits.)
Figure 2. Comparison of Visit-Level Demographic and Geographic Variables: Axon Registry 2019, NAMCS 2012-2016, and MEPS 2013-2017. (95% Confidence Intervals given for MEPS and NAMCS estimates from survey-adjusted standard errors). * Other race defined as Asian, Pacific Islander, and Indigenous persons.

(95% Confidence Intervals given for MEPS and NAMCS estimates from survey-adjusted standard errors). EEG in MEPS pertains to years 2013-2015 only.
**Figure 4:** Participating Neurology Practices in Axon Registry in 2019 in the United States
(courtesy of Verana Health.) The percentage of all Axon Registry patients is indicated per state.
Table 1. Person-Level Comparison between Axon Registry and MEPS, 2019. (Abbreviations: n=person sample; N(wt)=nationally weighted estimate for population of people)

<table>
<thead>
<tr>
<th>Category</th>
<th>Variable</th>
<th>MEPS 2019 Estimate (95% Confidence Interval)</th>
<th>Axon Registry 2019</th>
<th>Cohen’s $h$</th>
<th>Wald Test non-linear hypothesis $H_0$: MEPS19=Axon19 (p-value)</th>
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<tr>
<td>Sample</td>
<td>n</td>
<td>924</td>
<td>645,127</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>N(wt)</td>
<td>10.0m (9.2m-11.0m)</td>
<td>645,127</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Birth Sex</td>
<td>Female</td>
<td>0.57 (0.54-0.61)</td>
<td>0.6</td>
<td>0.06</td>
<td>0.13</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Age:</td>
<td>&lt;15 years</td>
<td>0.07 (0.05-0.09)</td>
<td>0.02</td>
<td>0.23</td>
<td>&lt;0.0001</td>
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<tr>
<td></td>
<td>15-24 years</td>
<td>0.05 (0.03-0.06)</td>
<td>0.05</td>
<td>0</td>
<td>0.66</td>
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<tr>
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<td>25-44 years</td>
<td>0.17 (0.14-0.21)</td>
<td>0.18</td>
<td>0.03</td>
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<tr>
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<td>45-64 years</td>
<td>0.34 (0.31-0.38)</td>
<td>0.32</td>
<td>0.04</td>
<td>0.24</td>
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<tr>
<td></td>
<td>65-74 years</td>
<td>0.21 (0.18-0.24)</td>
<td>0.21</td>
<td>0</td>
<td>0.81</td>
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<tr>
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<td>&gt;=75 years</td>
<td>0.16 (0.14-0.19)</td>
<td>0.21</td>
<td>0.13</td>
<td>0.0006</td>
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<tr>
<td>Race:</td>
<td>White</td>
<td>0.82 (0.79-0.85)</td>
<td>0.84</td>
<td>0.05</td>
<td>0.15</td>
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<tr>
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<td>Black</td>
<td>0.10 (0.08-0.12)</td>
<td>0.11</td>
<td>0.03</td>
<td>0.45</td>
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<tr>
<td></td>
<td>Other race</td>
<td>0.08 (0.06-0.10)</td>
<td>0.05</td>
<td>0.12</td>
<td>0.001</td>
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<tr>
<td>Ethnicity:</td>
<td>Hispanic</td>
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<td>0.07</td>
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<td>Neurological Conditions:</td>
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<td>0.18</td>
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<td>Epilepsy</td>
<td>0.13 (0.10-0.15)</td>
<td>0.10</td>
<td>0.09</td>
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<td>Cerebrovascular Disease</td>
<td>0.08 (0.06-0.09)</td>
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<td>0.10</td>
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<td>Multiple Sclerosis</td>
<td>0.05 (0.03-0.06)</td>
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<td>0.05</td>
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<td>Parkinson’s Disease</td>
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<td>Dementia</td>
<td>0.06 (0.04-0.08)</td>
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<td>Spine Pain</td>
<td>0.28 (0.24-0.32)</td>
<td>0.26</td>
<td>0.05</td>
<td>0.95</td>
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<tr>
<td></td>
<td>Polyneuropathy</td>
<td>0.08 (0.06-0.10)</td>
<td>0.08</td>
<td>0</td>
<td>0.95</td>
</tr>
<tr>
<td>Procedures:</td>
<td>MRI/CT</td>
<td>0.08 (0.06-0.10)</td>
<td>0.08</td>
<td>0</td>
<td>0.79</td>
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Table 2. Missing data by variable across data sources

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<tr>
<td>Age</td>
<td>0.0%</td>
<td>&lt;0.1%</td>
<td>&lt;0.1%</td>
<td>0.00%</td>
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<tr>
<td>Birth Sex</td>
<td>*</td>
<td>*</td>
<td>*</td>
<td>&lt;0.1%</td>
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<tr>
<td>Race</td>
<td>33.2%</td>
<td>*</td>
<td>*</td>
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<tr>
<td>Ethnicity</td>
<td>35.8%</td>
<td>*</td>
<td>*</td>
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<tr>
<td>Geographic Census Region</td>
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<td>0.4%</td>
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<tr>
<td>Diagnosis</td>
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<td>5.9%</td>
<td>5.1%</td>
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<td>Procedures</td>
<td>0.0</td>
<td>1.4%**</td>
<td>0.9%**</td>
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*Missingness and imputation rate not reported

**MR/CT for all data years, EMG not available in MEPS, and EEG pertains only to years 2013-2015
## Appendix 1. Authorship and Contribution

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<thead>
<tr>
<th>Author</th>
<th>Location</th>
<th>Contribution</th>
</tr>
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<tr>
<td>Andrew Wilson, MD, MS,</td>
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</tr>
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<td>Angeles VA Healthcare System</td>
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<td></td>
<td></td>
</tr>
<tr>
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</tr>
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</tr>
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</tr>
<tr>
<td>MS, PhD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Authors</td>
<td>Institutions/Departments</td>
<td>Contributions</td>
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<tr>
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<td>Verana Health, San Francisco, CA</td>
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<tr>
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<td>Emory University, Atlanta, GA</td>
<td>Design of study, analysis and interpretation of the data, drafting and revising the manuscript</td>
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<tr>
<td>Kavita V. Nair, PhD, FAAN</td>
<td>University of Colorado, Denver, CO</td>
<td>Design of study, analysis and interpretation of the data, drafting and revising the manuscript</td>
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<tr>
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<td>West Haven VA Medical Center, West Haven, CT</td>
<td>Design of study, acquisition of data, analysis and interpretation of the data, drafting and revising the manuscript</td>
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WNL-2023-000414_eapp2 --- [http://links.lww.com/WNL/D2](http://links.lww.com/WNL/D2)
References:

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29. Weissman AS, Ranpariya V, Fleischer AB, Jr., Feldman SR. How the National Ambulatory Medical Care Survey has been used to identify health disparities in the care of patients in the United States. J Natl Med Assoc 2021;113:504-514.


**Examining the National Representativeness of the Axon Registry: A Neurology-Specific Patient Registry**

Andrew M. Wilson, Karen B. Lundgren, Becky Schierman, et al.

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